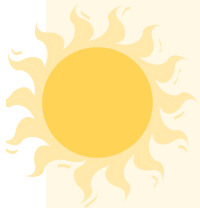


Inside this issue

Celebrating 3
 Parent2Parent 4
 A legal voice 5
 Inside Autism Delaware 6-7
 Cape Henlopen student
 voted Miss Spirit 8
 Calendar & events 8-9



Our mission

Autism Delaware™ works to create better lives for people with autism and their families in Delaware.



The Sun

Newsletter

January–March 2012

Off the back burner

Autism Delaware™ often has to let a few things simmer on the proverbial back burner until we find time to address them adequately. Now's the time! In this issue, we're looking at guardianship for adult children, getting transportation services or reimbursement, and financial planning.



Guardianship of adult children

If your child is legally an adult and unable to fully care for him- or herself, you need either to be appointed as your child's guardian or have someone else appointed. In Delaware, guardianship of an adult with a disability is granted by the state's Court of Chancery. To call in

- New Castle County: (302) 255-0544
- Kent County: (302) 736-2242
- Sussex County: (302) 856-5777

But you can find all the forms you need—plus instructions on what to do before, during, and after the guardianship hearing—at www.courts.delaware.gov. **Note:** The site is set up so you can petition for guardianship on your own, but if the guardianship can be contested, you should contact an attorney.

Step one—Go to www.courts.delaware.gov. Click on "Court of Chancery" and then "Guardianship" and "Forms." The forms you need, including medical and financial forms, are listed as a packet under "Guardianship of a person only." Print out the forms, fill them out, and get the signatures notarized. Then, present the completed forms to the court for filing.

One of the forms, Consent and Waiver of Notice, needs to be signed by all the next of kin (for example, parents and adult siblings). If all the next of kin have been sent this form but have not returned it in time for the hearing, then download and fill out the

Affidavit of Mailing to submit, also. Another form, Physician's Affidavit, is for your adult-child's physician to complete.

Note: All signatures must be notarized, and the signer must be in the presence of a notary public before signing any form. In Delaware, attorneys are also notaries public, so you may contract this service with either your attorney or a notary public.

The filing fees are currently \$115 for the petition and a \$2.00-per-page scanning fee, all of which is due and payable to the court upon filing the petition.

Step two—The court appoints an attorney ad litem to act as the lawyer for your adult-child. The attorney ad litem then meets with you (or the applying guardian) and your adult-child, and files a report with the court describing the situation. If the guardianship is uncontested, then the applying guardian pays the attorney's fees, which usually run \$300–750. **Note:** If this fee is out of your financial reach, ask the court about appointing an attorney who will work for free (pro bono). This request may not be possible, but asking never hurts.

At the hearing, the master (or judge) reviews the petition, other relevant forms, and the attorney ad litem's report. If all the papers are complete and no one

Continued on page 10

The Sun

A publication of Autism Delaware™

Email: delautism@delautism.org
Website: www.delautism.org

Autism Delaware main office

924 Old Harmony Rd. Suite 201. Newark DE 19713
Phone: 302.224.6020
Fax: 302.224.6017

Executive Director: Theda Ellis
theda.ellis@delautism.org

Associate Director: Teresa Avery
teresa.avery@delautism.org

Policy & Walk Director: Kim Siegel
kim.siegel@delautism.org

Asperger's Resource Coordinator: Heidi Mizell
heidi.mizell@delautism.org

Office Manager: Margie Rowles
margie.rowles@delautism.org

Communications Coordinator: Carla Koss
carla.koss@delautism.org

Office Assistant: Deanna Principe
deanna.principe@delautism.org

Southern Delaware office

16394 Samuel Paynter Blvd. Unit 201. Milton DE 19968
Phone: 302.644.3410

S. Delaware POW&R Coordinator: Melissa Martin
melissa.martin@delautism.org

S. Delaware Service Coordinator: Dafne Carnright
dafne.carnright@delautism.org

Admin. & Event Assistant: Amanda Jackson
amanda.jackson@delautism.org

Autism Delaware officers

President: Rob Gilsdorf
robdelautism@aol.com

Vice President: Marcy Kempner
marcy.kempner@me.com

Treasurer: Thane Martin
tmartin1971@hotmail.com

Secretary: John Fisher Gray
john.fisher.gray@post.harvard.edu

The Sun Editorial Committee

Theda Ellis Teresa Avery
Dafne Carnright Cory Gilden
Carla Koss Heidi Mizell
Jen Nardo

Autism Delaware™ is interested in a variety of viewpoints about autism and emerging research, but reference to any treatment, therapy option, program, service, or treatment provider is not an endorsement. We publish information only for informational purposes and assume no responsibility for the use of any information. You should investigate alternatives that may be more appropriate for your specific needs.



Rob Gilsdorf
President

At the end of December 2011, I finished my fourth and final year as president of Autism Delaware™. So much has happened in four years. We asserted our independence and became an unaffiliated nonprofit focusing on the Delaware autism community. We launched POW&R™ into its service delivery phase and, most recently, we became a truly statewide organization as we welcomed the Lower Delaware Autism Foundation into Autism Delaware.

Many more exciting developments are on their way, including efforts to offer clinical services and residential options for our community. As two of the many new services and supports ahead of us, our work is never finished!

We have an incredible professional staff and board of directors at Autism Delaware. They consist of some of the most talented and driven leaders in the state and are the reason we have been so successful over the years. Thank you, dear colleagues, for making

my time here a most enjoyable and memorable experience.

I have also met so many great people working for Autism Delaware, and I want to thank you all, too, for your friendship and support over the years. After nine years on the board, though, I find it is time for some personal respite. However, as many of you know, I do not sit still very well. I will chair the Autism Delaware Advisory Board. Count on me to stay involved. The question is not "if" but "how."

For me, having an outlet in which to contribute made all the difference over the years. I honestly feel that I am a better person because of the challenges we faced. As we all know, parenting an autism-affected family is difficult. And I always say "We did not volunteer for this gig; we were drafted."

Autism Delaware allowed me to redirect the energy associated with despair and frustration into positive outcomes for my family and community. I would encourage you to do the same. After "family" consider "service" as your next priority. I can assure you that a tremendous sense of accomplishment and well-being will follow.

I hope to see you soon!

A farewell is necessary before you can meet again. And meeting again, after moments or lifetimes, is certain for those who are friends.

—Richard Bach

A service of Autism Delaware



- Katina Demetriou**, POW&R Director
katina.demetriou@delautism.org
Bus: 302.224.6020 Ext. 206 **Cell:** 302.824.2252
- Karen Anderson**, N. Delaware POW&R Coordinator
karen.anderson@delautism.org
Bus: 302.224.6020 Ext. 209 **Cell:** 302.824.2253
- Melissa Martin**, S. Delaware POW&R Coordinator
melissa.martin@delautism.org
Bus: 302.644.3410

Delaware General Assembly returns to action January 10

As always, when the Delaware General Assembly returns to session, Autism Delaware will be there! We will advocate for increases in funding for adult services to ensure that providers can keep their doors open and their clients well-served. We will also watch budget developments to ensure that Department of Health and Social Services Secretary Rita Landgraf's requested funding for new graduates of special schools (like DAP) and emergency placements are included in the Division of Developmental Disabilities Services' budget. And throughout the session, we will monitor new issues that arise with the potential to affect the autism community.

For the third year running, we will pursue passage of a bill that requires state-regulated health insurers to cover autism therapies. Senate Bill 22 will bring much-needed relief to families struggling to get the care that their children need. The bill should also provide an incentive for board-certified behavior analysts, speech language pathologists, and other professionals to practice in Delaware as well as result in lower levels of needs to be met in state systems. The bill sits now with the senate finance committee, where it died in 2010 awaiting a cost estimate and a vote.

Get in the action!

SB22 is a classic example of how Autism Delaware's voice is only as loud as yours—the community of people with autism

and those who care about them. This bill will have a cost, and legislators need to know that their constituents think that providing therapies to children with medical disorders is worth it. Autism Delaware can make our legislators HEAR this, but it takes you—your calls, emails, letters, and visits—to make our legislators BELIEVE it.

Our Autism Action kit is in the Advocacy section of Autism Delaware's website—www.delautism.org—and includes lots of information on things you can do to communicate with your legislator. Why not download the kit and try two of its ideas before National Autism Awareness Month in April?

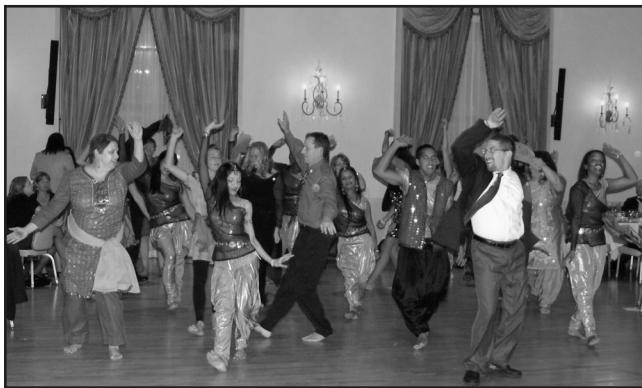
To learn who your legislator is, go to www.congress.org. Gather some friends, and have a letter-writing party. Bring your neighbors to a coffee hour with your legislator. Autism Delaware is happy to offer advice and support as you advocate for your loved one with autism. And we hope to see you at Legislative Hall!



Legislative Hall, Dover

Celebrating at two auction and gala events

This year, Autism Delaware held two auction and gala events in November to help fund our statewide operations.



Autism Delaware staff and volunteers joined the Jhankaar Bollywood Dancers for the entertainment finale.

not only an incredible auction but a sundae bar and grooving to the tunes of Delaware's own Love Seed Mama Jump.

Thank you!

Our volunteer-run auction events are critical parts of our yearlong fundraising. A huge *thank you* goes out to each and every one of our volunteers, corporate supporters, and guests who made both events successful.

On November 12, we "brought down the house" at the Dupont Country Club in Wilmington with Bollywood Magic. The Bollywood-themed event featured henna tattoos and a troupe of Bollywood dancers who were joined by our own staff and volunteers for the finale.

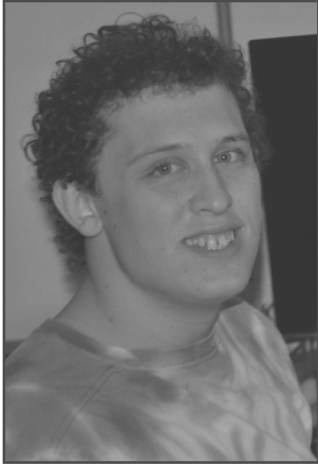
The next weekend, November 19, we kept the party going at the Bay Center in Dewey Beach with our ILLUMINATE auction and gala event. Blue-jeans-and-bling attire made this event extra special, and guests enjoyed



Decked out in blue jeans and bling are (L to R) 2011 Autism Gala & Auction Co-chair Koh Morrisey and Autism Delaware Board of Directors members Tom Forrest and Dorian Rowe Kleinstuber who is also an auction co-chair.

PARENT PARENT

Written by parents for parents



Daniel Kee

As the parents of Daniel Kee, Jim and I became increasingly aware over the years that our son would remain a “little boy” for a very long time. He was not acquiring the social and cognitive skills necessary to function independently. As he approached adulthood, Jim and I worried that public behaviors, similar to those of a misbehaving child, would be considered disruptive and get him in trouble.

Even worse, we worried

that Daniel could refuse necessary medical treatment as an adult. Guardianship seemed essential to protect and care for Daniel.

Initial inquiries into guardianship resulted in warnings from other parents that the process would be difficult, cost thousands of dollars in legal fees—and require Daniel to testify. “Oh, my!” I worried. “How are we going to do this?”

With Daniel's 18th birthday looming, I took a deep breath and contacted a lawyer. During a single consultation with Jim and me, the lawyer explained the process, evaluated our situation, and answered our questions. Most importantly, she relieved our fears and convinced us that we could do this ourselves—and we did.

The folks at the Delaware Court of Chancery were very courteous and helpful in guiding us through the process. They appointed an attorney to represent Daniel—and to meet with him alone! “This will be interesting,” I thought to myself with raised eyebrows.

Then, the court-appointed attorney met Daniel and realized that a visit alone with him would not be productive. So, we all met together and answered questions that triggered stories about our daily lives. The visit was very comfortable, and I think the attorney could easily see the need for guardianship. A hearing was scheduled within the week.

The day of the hearing began as a beautiful morning, and the fabulous view from the top floor of the courthouse helped to calm us before we took our seats in the partially-filled courtroom. When called, Jim and I went up to the podium while Daniel stayed in his seat. Daniel was not required to be there, let alone testify, but his presence felt supportive.

The first thing the judge did was thank us on behalf of the court for loving Daniel and continuing to care for him. We got quite emotional as we explained that we wouldn't have it any other way. We are fortunate that Daniel, now 20, is a loving young man who is enjoyable to be around.

The judge went on to formally describe the responsibilities associated with guardianship—and then, the hearing was over. Happy and relieved, we celebrated at lunch before heading to Daniel's favorite place: home.

—Cecilia Kee

Welcome new members!

Your membership supports our mission. In other words, you help Autism Delaware's effort to create better lives for Delawareans with autism spectrum disorders (ASDs) and their families.

Norma Brister
Child HELP Foundation
Robert Clark & Danielle Saienni
Dorothy Davis
Victor & Margaret DeGeorge
Pat & Debra Heffeman

Mr. & Mrs. Derrick Layfield
Mr. & Mrs. Edward Meehan
Debbie Morrison
Joe Robinson
Mr. & Mrs. Brian Snyder

Respite!

If you're caring for an individual of any age with a disability, you can find help with respite care online at www.delrespite.org or by calling (888) 610-5572.

Apply for financial assistance to fund your respite care at www.delrespite.org, or get a hard copy of the application by calling (302) 324-4444, ext. 2087.

A legal voice for people with autism

by Tim Hudson

The 2011 National Autism Conference, held at The Penn Stater Conference Center Hotel in State College, Penn., in August, created an atmosphere of support, understanding, and learning that is valuable to those who interact on a daily and near-daily basis with children and young adults with autism spectrum disorders (ASDs).

Thanks to a \$250 Autism Delaware™ Conference Stipend, Tim Hudson was able to attend this conference and to take

For info on the stipend, visit www.delautism.org.

away from it a rejuvenated sense of direction and some eye-opening facts.

The most-illuminating presentation at the 2011 National Autism Conference was delivered by the keynote speaker, lawyer and mother of three Lorri Unumb, Esq. Unumb wrote the autism insurance legislation for South Carolina that passed in 2007. Known as Ryan's Law (for Unumb's child with an ASD), the legislation serves as a catalyst for the national movement toward autism insurance reform. A consultant today for a number of different organizations, including Autism Speaks, Unumb addresses the legal aspects of autism and how they have not kept pace with the day-to-day problems faced by people with ASDs and their parents.

During Unumb's keynote speech, the two most eye-opening facts involved how insurance companies are not keeping pace with treatments for ASDs and how legal practices are not equipped to handle the future influx of young adults diagnosed with ASDs.

Insurance coverage

According to Unumb, Indiana was the first state to enact a law that says insurance companies have to cover children diagnosed with ASDs—and this was in 2004, only after one of Indiana's Congressional representatives had a grandson diagnosed with an ASD. Today, fewer than 30 states in the country have laws on the books that make it illegal for insur-

ance companies to deny coverage to children with ASDs or funding for doctor-recommended best practice services.

Sadly, Delaware is not one of these states. Unumb's presentation included five principles that parents and advocacy groups can use to persuade Delaware's politicians to adopt a law:

First, don't over-reach. Be sure to know, as a group, what you are looking for and what compromises you can live with.

Second, come together as a group. Do not allow rifts to form within your autism community.

Third, re-think what you know. Stay up to date on best practices currently in use and what laws have been passed in other states. This information can be invaluable in formulating a law for Delaware.

Fourth, educate your politicians. Explain your concept to politicians in clear, understandable terms.

Lastly, use your ABA techniques. Applied behavior analysis calls for positive reinforcement, so write a thank-you note to any politician who meets with you and a press release noting that this politician met with concerned parents. Include a photo of the politician with your children. Then, send the release and photo to your local and state newspapers. Every politician likes good press.

Legal practices

In addition to Unumb's discussion of insurance coverage, the autism advocate also talked about the future influx of young adults with ASDs in relation to current legal practices. Citing one case in particular, Unumb noted the lack of precedent-setting cases that allow autism to be used as a defense. In this case, a defendant's lawyer used an autism diagnosis as a defense against the charges—and the defendant was released because no precedent had been set.

Imagine if this defense were used repeatedly, urged Unumb. Do you think autism will be given the attention it deserves? And what if the autism defense is eventually denied? If your child with autism were arrested and could not explain his or her behavior, would your child go to jail? These are questions that have not been raised before but need to be discussed as our children grow up and become young adults. And we need to present these issues to our lawmakers.

For more information, log onto www.autismvotes.org.

Would you like some financial help with school or career?

Every spring, Autism Delaware™ awards \$1,000 scholarships and stipends to eligible individuals who promise to bring their unique skills to the autism community:

- **Gray Memorial Scholarship**—for UD students planning to become professionals in the autism community

- **Para-to-Educator Stipend**—for paraprofessionals who, in the last year, completed their educations to become teachers of children with ASDs
- **Adult with Autism Scholarship**—for adults with ASDs who want a post-secondary education

Applications are due in the Autism Delaware main office by January 20, 2012. Get an application at www.delautism.org.

INSIDE **Autism Delaware** by Theda Ellis, MBA, MEd

Planning for a second associate director

In planning for my retirement next year, the Autism Delaware™ Board of Directors decided to hire a second associate director in the spring. This new director will work with our current associate director, Teresa Avery, and me during an approximately eight-month-long transition phase. During this phase, I will be working only three days a week, concentrating on service and program development, while Avery, currently responsible for development and communications, will assume my management and fiscal responsibilities.

To fill the new associate director position, the board will look for an autism specialist who can oversee the development of programs and services for children and adults with autism. The new director's goal will be to develop a plan for Autism Delaware to become a residential service provider—for adults initially, but this plan will also review the need for services for children. Our long-term goal is to help the state keep Delaware's children in the state. By the time this newsletter is printed, you'll see this position posted on our website.

Announcing a new clinical director

For more than a year, we researched the possibility of Autism Delaware offering applied behavior analysis (ABA). Today, we're happy to announce, we are starting a three-year pilot program, and Susan L. Peterson, PhD, BCBA, will step into the new role of Autism Delaware's clinical director. Peterson will be joining us on a half-time basis in early 2012, but we anticipate that this service will grow over time.

Some of you are familiar with Peterson from her time at the Brennen School and Pyramid Educational Consultants. For those of you who don't know her, Peterson is a clinical psychologist, certified school psychologist, and board-certified behavior analyst (BCBA). She worked with Autism Delaware previously while developing the Best Practice Study for Adults with Autism that served as the basis for our employment services, POW&R™. In her capacity as Autism Delaware's new clinical director, Peterson will work with POW&R in overseeing behavior support plans. She will also be available on a fee-for-service basis to provide diagnostic services, functional behavioral analyses, individual education evaluations, consultations with school districts, and parent training as well as to develop and oversee the implementation of behavioral plans.

Expanding office space

Autism Delaware is expanding so much that we need more space. Early in the new year, we are taking over added floor space in the same building as our current New Castle County office. With the additional space, our associate directors, POW&R director, Asperger's resource specialist, and the new clinical director will now have much-needed private work space. We will also now have work space for the many folks who come to volunteer on a regular basis.

Sharing your comments

Looking to the future, we will continue to share our plans with you. Please feel free to share your plans and comments with us at delautism@delautism.org.

Dust off your sneakers!

Every April, the autism community and our families and friends gather to show our commitment to the cause and to raise funds to keep Autism Delaware's services going and growing. At this year's two-day Walk for Autism, let's aim for a big finish: \$200,000!

Walk!

All walkers are welcome. Walking is free, but we strongly encourage you to raise as much as you can. Raise \$100 to start earning prizes! And after you walk, celebrate with food, music, exhibits by local resources, crafts, and children's activities.

Most people put together teams—which is a great way to build awareness for autism's impact on families. Get into the spirit with signs, matching shirts, or some other way that celebrates your loved one with autism.



2012 Walk for Autism

April 21, 2012
Bellevue State Park
Wilmington

April 22, 2012
Cape Henlopen State Park
Lewes

In 2012, we are focused on expanding this event as a walk to make the event as accessible as possible to all families and community members. If you'd like to support Autism Delaware through running or other athletic pursuit, let us know.

To learn more about the Walk for Autism or to sign up, visit www.delautism.org.

Sponsor!

Sponsorships are available for any size business or organization and come with various forms of recognition—often statewide. Your company or organization may also want to exhibit at one or both sites, and spaces are included in several packages. In-kind donations may qualify for sponsorships. For more information, contact (302) 224-6020, ext. 204.

Volunteer!

The Walk for Autism attracts more than 2,200 people—which requires a lot of help to coordinate. Volunteers are needed for pre-event planning, promotion, event setup and breakdown, and day-of event activities. To help, send an email to walk-raceforautism@delautism.org.

Getting a job and getting paid in Kent Co.



Tony Prouse

Kent County resident Tony Prouse came to POW&R™ with a specific goal: "Get a job, and get paid."

To this end, Tony has participated for the last two months in a paid training program with Dover Downs Hotel and Casino.

Two of POW&R's direct support professionals, Lisa Crouch and Rachel Donaldson, have helped Tony learn how to do his job as a house attendant, supporting him with task lists and navigation

through the policies and procedures for hotel staff. Not only did Tony learn all aspects of the job (including assisting guest room attendants with removal of soiled linens and taking out trash and room service items), but he also learned how to keep the pool and gym areas tidy and stocked with towels and to ensure that the hotel's Platinum Lounge is spotless and fully stocked for use by the hotel's VIP guests.

At the end of October, Tony's supervisors told POW&R's staff that Tony was doing a great job and is a valuable team player. Officially hired as an employee of Dover Downs Hotel and Casino, Tony does his job with pride—and gets paid!



The New Castle Police, Fire, Rod & Gun Club presented Autism Delaware™ on September 27 with a check for nearly \$3,000. To raise the money, the motorcycle enthusiasts circled northern New Castle County during the Annual Autism Run and "Ride to Know." Presenting the check are (left to right) club members Patty Starver, Dave Starver, Rick "Pop" Smith, Darryl Hayes, Joni Smith, and Eugene "Chief" Stoops. Receiving the check is Autism Delaware's associate director, Teresa Avery (far right).

My family went to the skating event you held on Saturday [Sept. 17, 2011].... Thank you all from the bottom of my heart. I cannot remember a time my whole family had so much fun.... The fact that my kids can be who they are with no one staring or judging—and the cost was so low—it is unbeatable.

—Carla Lane

Honor our volunteers

Many wonderful people make a difference in the autism community every day. They volunteer their time and expertise to chair fundraising events, organize social activities, raise public awareness, and advocate for change, and they do it all to improve the quality of life for all Delawareans living with autism spectrum disorders (ASDs).

Help Autism Delaware™ honor these volunteers and their outstanding efforts by nominating the recipients for this year's awards:

- Outstanding Autism Delaware Volunteer
- Outstanding Leader in the Community
- Outstanding Employer

Download a nomination form at www.delautism.org. For a print copy, call (302) 224-6020. And be sure to call in time to make the January 6 deadline!

Members only!

To nominate a volunteer for one of this year's awards, you must be a member of Autism Delaware™.

To become a member, visit www.delautism.org. Or call (302) 224-6020.



Rec4All is a program Autism Delaware started in October 2009 as a collaboration of groups and agencies that want to provide recreational and social opportunities to all people in the disabilities community. Our mission is to increase these recreational and social experiences across the life span and across the state. To advertise Rec4All's opportunities, we created a calendar page on the Autism Delaware website in which all Rec4All groups can share their events. You can find the calendar at <http://tiny.cc/vlw9y>. Please feel free to share your group's activities by contacting heidi.mizell@delautism.org or by calling (302) 224-6020, ext. 205.

Cape Henlopen student voted Miss Spirit



Rose Campbell

Rose Campbell was voted Miss Spirit for the Cape Henlopen High School Homecoming on October 14. Her friends from Best Buddies and her sister Elena lobbied classmates for votes.

"Rose was self-motivated to run," says her mother, Cynthia Gratz Campbell, "and put up posters at school.... She was thrilled and thanks all her friends and the Cape community for their support."

CALENDAR of EVENTS

January

- 4, 11, 18, 25**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 P.M. *Registration:* Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.
- 10**—Parent Coffee Hour. Panera Bread. Wilmington. 7:00 P.M.
- 13**—Parent Coffee Hour. Holiday Inn Express. Seaford. 9:00 A.M.
- 13**—Teen/Tween Asperger's game night at Autism Delaware:
 - Main office. 6:30–8:30 P.M. *Registration:* Heidi Mizell @ (302) 224-6020, ext. 205.
 - Southern Delaware office. 6:00–8:00 P.M. *Registration:* Dafne Carnright @ (302) 644-3410.
- 14**—Sensory friendly movie. Regal Cinemas. 1100 Peoples Plaza. Newark. 10:00 A.M.

February

- 1, 8, 15, 22, 29**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 P.M. *Registration:* Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.
- 8**—Parent Coffee Hour. Georgia House Restaurant. Milford. 9:00 A.M.
- 14**—Parent Coffee Hour. Panera Bread. Wilmington. 9:00 A.M.
- 17**—Teen/Tween Asperger's game night. 6:30–8:30 P.M. Autism Delaware main office. *Registration:* Heidi Mizell @ (302) 224-6020, ext. 205.
- 24**—Teen/Tween Asperger's game night. 6:00–8:00 P.M. Southern Del. office. *Registration:* Dafne Carnright @ (302) 644-3410.

March

- 6**—Parent Coffee Hour. Arby's. Lewes. 9:00 A.M.
- 7, 14, 21, 28**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 P.M. *Registration:* Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.
- 10**—Skating party. Milford Skating Center Roller Skating Rink. 1 Park Av. Milford. 5:30–7:30 P.M.
- 13**—Parent Coffee Hour. Panera Bread. Wilmington. 7:00 P.M.
- 16**—Teen/Tween Asperger's game night. Southern Delaware office. 6:00–8:00 P.M. *Registration:* Dafne Carnright @ (302) 644-3410.
- 23**—Teen/Tween Asperger's game night. Autism Delaware main office. 6:30–8:30 P.M. *Registration:* Heidi Mizell @ (302) 224-6020.



Parent Coffee Hour

Panera Bread

3650 Kirkwood Hwy.,
Wilmington
Jan. 10 @ 7:00 P.M.
Feb. 14 @ 9:00 A.M.
Mar. 13 @ 7:00 P.M.

Join us!

Holiday Inn Express

24058 Sussex Hwy.,
Seaford
Jan. 13 @ 9:00 A.M.

Georgia House Restaurant

18 S. Walnut St., Milford
Feb. 8 @ 9:00 A.M.

Arby's

1155 Hwy. One, Suite 5018,
Lewes
Mar. 6 @ 9:00 A.M.

The coffee's on us!



Mark your calendar!

April is National Autism Awareness Month

Get ready to advocate, educate, and fundraise for autism.

For more, visit www.delautism.org.

Teen/Tween Asperger's game night

For 9–19 year olds with Asperger's syndrome

Place: Autism Delaware™ main office

Dates: January 13
February 17
March 23

Reservations:
Heidi Mizell
(302) 224-6020
heidi.mizell@delautism.org

Time: 6:30–8:30 P.M.

For 9–14 year olds with Asperger's syndrome

Place: Autism Delaware™ So. Del. office

Dates: January 13
February 24
March 16

Reservations:
Dafne Carnright
(302) 644-3410
dafne.carnright@delautism.org

Time: 6:00–8:00 P.M.

Lego® Club

For children who have good communication skills and can follow directions.

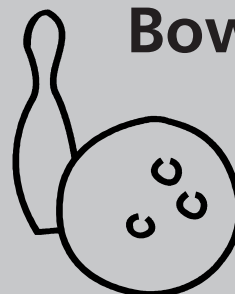
Evaluation required.

Call Heidi Mizell at (302) 224-6020, ext. 205.
Or send an email to heidi.mizell@delautism.org.
Or visit www.delautism.org.



Winter 2012 session

Begins January 10



Bowling night

Every Wednesday
5:30–7:00 P.M.

Bowlerama
3031 New Castle Av.
New Castle, Del. 19720-2297

To register, email Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.

Off the back burner Continued from page 1

contests the petition, the master signs the petition. The guardianship is now final.

If anything goes wrong during these two steps (for example, someone contests the guardianship or the forms are incomplete), additional steps are necessary. At this point, hiring an attorney is your best bet.

Step three—With guardianship finalized, the guardian sets up a bank account in a Delaware bank for your adult-child. **Note:** The guardian should keep a copy of the court’s order on hand to prove his or her right to make decisions regarding your adult-child.

The guardian submits a yearly financial inventory to the court. For any expenses made with your adult-child’s money, receipts must be presented with the inventory. The guardian must also make yearly submissions to the court, noting where everyone is living (geographic report) as well as a medical report. A medical report form is also available at www.courts.delaware.gov/chancery. Click on “Guardianship” and “Forms,” and look for the list for the “Annual Update of Medical Report.”

Getting transportation services or reimbursement

Once you have a family member diagnosed with an autism spectrum disorder (ASD), you find yourself circling the state to visit doctors, therapists, and specialists. Instead of dealing with rising gas prices, you can either have a service transport you or you can get reimbursement for your travel expenses. Either way, call Logisticare Transportation of Delaware at (866) 412-3778.

“If you want to get reimbursement for transportation,” advises Cory Gilden whose son has an ASD, “claim financial hardship as your reason for needing reimbursement. Logisticare will send you a mileage reimbursement form, and you’ll have to call to get a trip number for each doctor or therapy appointment.

Continued on page 11

Social Security Income (SSI)

Apply for your child or adult-child with autism.

Your child (under age 18) with autism may be eligible for SSI if he or she meets the Social Security Administration’s (SSA’s) definition of disability for children, plus allowable income and resources fall within the eligibility limits. Because SSI is a needs-based benefits program, eligibility is based on two categories of assets:

- **Income** refers to the amount of money a person receives from wages, benefits and food assistance programs, pensions, and so on. The child must not have earned more than \$1,000 a month in 2011.
- **Resources** refer to the value of assets, such as cash savings, equity, or real estate. For the individual, the resource limit is \$2,000, and the family limit is \$3,000.

SSA considers your child’s income and resources as well as those of family members living in the child’s household.

What happens when your child reaches 18? Both the medical and non-medical rules and eligibility criteria for SSI change, so an 18 year old with autism who was not previously eligible for SSI may now be. Likewise, if this adult-child had been receiving SSI, he or she will now be reviewed and re-evaluated for eligibility purposes based on adult rules.

The biggest difference: Family income and resources no longer matter when the child reaches 18. Only the young adult’s income and resources count towards eligibility. (See the second bullet above, Resources.)

SSI is particularly important because it not only provides some income but is also required for Medicaid eligibility. Medicaid is the primary health insurance for children and adults with disabilities. It’s also the gateway to adult services. All residential services are provided under a Medicaid waiver, so to get some key services, an adult must be eligible for SSI and Medicaid. Currently, eligibility for Medicaid is not required for day or vocational services, but some consideration has been given to that end, so we encourage you to apply for SSI and Medicaid when your child reaches 18.

For more information, see <http://www.ssa.gov/pubs/10026.html>.

Now available

Revised parent packet

For families with children newly diagnosed with autism, we have created a comprehensive, new parent packet. Delivered digitally or in print, the information in this packet will help you understand autism spectrum disorders and the Delaware school system and provide a wealth of resources available in Delaware and the surrounding states.

For more, call Heidi Mizell at (302) 224-6020. Or email her at heidi.mizell@delautism.org.

Announcing

New players in Delaware

Jane Gallivan

Director, Delaware Health & Social Services,
Division of Developmental Disabilities Services

Phone: (302) 744-9620

Email: jane.gallivan@state.de.us

Mary Ann Mieczkowski, M.S.

Director, Delaware Department of Education,
Exceptional Children Resources

Phone: (302) 735-4210

Email: mmieczkowski@doe.k12.de.us

Continued from page 10

“Make sure you call 48 hours ahead of time,” adds Gilden, “and have handy your child’s Medicaid number, the address of where you are going, the date and time of the appointment, and the physician’s or clinician’s name and number.”

Financial planning

Financial planning for your child with autism can take many forms. The goal is to plan for your child’s financial needs before he or she nears transition age. One option is a special-needs trust.

Also known as a supplemental needs trust, a special-needs trust is a legal document prepared for the benefit of an individual with disabilities. The document allows an unlimited amount of assets to be held in trust. In a special-needs trust, the assets are not countable when determining government benefits, such as supplemental security income, Medicaid, subsidized housing, and vocational rehab.

Here are some steps to setting up a special-needs trust:

- Create a letter of intent, defining your intentions for your child’s future quality of life in your stead.
- Meet with an estate planning attorney to set up the special-needs trust.
- Also, meet with your financial advisor to discuss ways to fund the trust and an amount that works for you. For an online calculator, visit totalmerrill.com/specialneeds.
- When the trust is set up and funded, monitor the investments in the trust to make sure they are working in line with your goals.
- Tell family members thinking about leaving assets to your child that the trust has been set up and to make a gift of the assets to the child through the trust.

Delaware developed its own special-needs trust legislation called the Delaware CarePlan (DCP). Administered by The Arc of Delaware, DCP works with families to determine how a trust should be used and to set up a plan of services. For details, visit <http://www.thearcofdelaware.org/homes/housing-support-programs/delaware-care-plan/> or <http://codes.lp.findlaw.com/decode/12/40>.

Some other sources that specialize in special-needs trusts are:

- Swarthmore Financial Services
www.swarthmorefinancial.com
- Diann Jones, Nationwide Insurance
www.specialneedsplanning.org/Credentials-of-Diann-Jones.1.htm
- Kevin M. Baird, Baird Mandalas LLC
www.bairdmandalas.com/?page_id=36
- Ryan Williamson, Merrill Lynch
www.totalmerrill.com/TotalMerrill/system/ViewFAPage.aspx?pageurl=Ryan_Williamson

Autism Delaware has scheduled various speakers to present a range of information about financial planning around your loved one with autism. For details, call (302) 644-3410, or visit www.delautism.org.

Frequently asked questions & where to get them answered

Q What safety precautions or programs are available for my child with special needs?

A For children who are flight risks, get handicap placards—http://www.dmv.de.gov/services/vehicle_services/reg/ve_reg_handicap.shtml

Special Needs Alert Program (SNAP)—<http://dhss.delaware.gov/dph/ems/emscsnap.html>

Voluntary registry through Delaware Emergency Management Agency (DEMA)—<http://www.de911assist.delaware.gov/>

Q How do I keep proper records of everything?

A Talk About Curing Autism (TACA)—<http://www.tacanow.org/family-resources/getting-staying-organized/>

Advice from the Kennedy Krieger Institute—http://www.iancommunity.org/cs/articles/the_importance_of_record_keeping

BBB Autism Support Network—http://www.bbbautism.com/pdf/article_49_record_keeping.pdf

Q Who pays for what?

A <http://www.tacanow.org/family-resources/who-pays-for-what-a-guide/>

State laws on insurance coverage—<http://www.ncsl.org/?tabid=18246>

Q What is respite, and how do I get it?

A Delaware Department of Health and Social Services—<http://dhss.delaware.gov/dsaapd/respite.html>

Delaware Lifespan Respite Care Network—<http://www.delrespite.org/>

Autism Delaware

New board of directors members

Marie-Anne Aghazadian

Executive Director, Parent Information Center (PIC) of Delaware, Inc.

Michael Graci (completing the president’s term)

Vice President of BlackRock, Inc.

Artie Kempner

Coordinating Director of NASCAR on FOX and founding member of Autism Delaware



924 Old Harmony Rd.
Suite 201
Newark DE 19713

www.delautism.org

Nonprofit Organization
U.S. POSTAGE PAID
Permit #317
Newark DE

Return service requested



Helping People and Families Affected by Autism

To pay by credit card
Visit www.delautism.org. And click the "Join today" button on the bottom left of the screen.
All membership fees and contributions are tax-deductible to the fullest extent allowed by law.

Make your check payable to Autism Delaware. Mail your check and application to:
Autism Delaware, 924 Old Harmony Rd., Suite 201, Newark DE 19713

My membership fee is \$ _____
I would also like to contribute this amount \$ _____
Total amount enclosed \$ _____

Becoming a silver, platinum, or lifetime member will make you a part of a select group of individuals who have demonstrated special leadership and a commitment to helping us meet our mission. As a leader in the support of autism and autism research, you will receive special recognition in our newsletter or other materials.

Yes! Please add my name to the mailing list to receive *The Sun* through DAP distribution. (This option is only for families who do not receive *The Sun* through DAP distribution.)

Other (Please describe): _____

I am a: Parent Family member Service provider Educator Medical professional Individual with autism

Name(s): _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: (h) _____ (w) _____ Email: _____

Enroll me in the following category:
 Individual \$20 Family \$25 Professional \$50 Silver \$100 Platinum \$300 Lifetime \$500
 I am a new member. I am renewing my membership.

Annual membership application